**Definitions, Description and Prevalence**  
*By Laurie Selz Campbell*

Autism is but one developmental disability in the range known as “autism spectrum disorders.” Other disorders in the autism spectrum include Asperger syndrome, Rett syndrome, and pervasive developmental disorder (PDD). The Centers for Disease Control (CDC) (2007) estimates that currently, about 1.5 million Americans have autism, with the disorder occurring in about 1 of every 150 children overall, and 1 in every 100 boys.

While the cause of autism remains unclear, there is some evidence that genetics play at least a partial role; when there is one child with autism in a family, there is a 1-in-20 likelihood that a second child will also have autism—considerably greater than the population likelihood above. Studies of the brain have shown differences between children with autism and those without in certain regions of the brain (CDC, 2007). While the symptoms of autism can range from quite mild to severe and disabling, there are, in general, certain clusters of behaviors that comprise the autism diagnosis (DSM-IV, 1994; National Institute of Neurological Disorders & Stroke, n. d.). These include:

1. **Social interaction and communication challenges**  
   - Avoiding eye contact, social play, and interaction  
   - Using repetition or imitation (echolalia) instead of the “give and take” of conversation  
   - Having difficulty understanding social cues or interpreting what others are communicating

2. **Extreme sensitivity to stimulation**  
   (touch and sound)

3. **Preoccupation with particular objects or topics**  
   - Greater than usual distress or anxiety related to transition or change

4. **Repetitive physical movements, which can be self-injurious**

In addition, many people with autism have been found to experience compromised immune system functioning, with greater susceptibility to common bacterial and viral infections, and impaired ability to mobilize antibodies or respond to typical medications. They tend to have greater than usual gastrointestinal sensitivity and a greater than usual likelihood of having food allergies (for example, wheat gluten and refined carbohydrates).
example, touch, smell, or noise), while seeming to be indifferent to other aspects of the environment (for example, toys or other people). The child may appear to prefer repetitive motor play to social or imaginative/pretend play. Language and communication skills may not develop as expected. Changes in routine can become extremely distressing for the child.

There is not a simple “test” to diagnose autism. Rather, the evaluation and diagnosis process incorporates direct observations of the child’s behavior, detailed input from parents and caregivers, and developmental observations from pediatricians or family doctors. Initial screening often occurs during a visit to the child’s pediatrician, and is followed by a more detailed diagnostic evaluation with a multidisciplinary team. A number of valid and reliable instruments have been developed to assist in screening and evaluation. For an overview of the diagnosis process and the instruments used, see the overview provided by the National Institutes of Mental Health, available at http://www.nimh.nih.gov/health/publications/autism/nimhautismspectrum.pdf, or the summary provided by the Autism Society of America, available at http://www.autism-society.org/site/PageServer?pagename=about_diag_screening.

### About 1.5 million Americans have autism, with the disorder occurring in about 1 of every 150 children overall, and 1 in every 100 boys.

### Strengths and Challenges for Families

The course of autism is quite variable, with some individuals able to lead lives that are relatively unaffected by the disorder, and others remaining quite disabled well into adulthood. In an effort to learn more about the lives of young adults with autism spectrum disorders, some researchers (Eaves, 2008; Howlin, Goode, Hutton, & Rutter, 2004) have followed the experiences of children with autism over time. Findings suggest that, while outcomes ranged considerably, many young adults experienced limited independence, financial vulnerability, and continuing behavioral issues. Mental health disorders, obesity, and epilepsy were relatively common in the group.

The literature on the rewards and challenges for families of living with a child with autism is abundant. Families have been studied over time, from the early years of evaluation and diagnosis until the child with autism reaches adulthood. Gray (2002, 2006) followed parents of children with autism over a ten-year period. She found that, while the early years of diagnosis and navigating the treatment system were often highly stressful, experiences of extreme stress tended to decrease over time, and perceptions of family well-being improved. Parents attributed these improvements to such factors as (a) improved ability to manage and adapt to the child’s behavior over time, (b) decreasing experiences of stigma from others outside (and even within) the family, and (c) relatively high levels of satisfaction with services.

However, Gray found that the improvement in perceived well-being was true only for families in which the autistic child did not have violent or aggressive behaviors. Parents with a violent or aggressive autistic child tended to remain highly stressed, both emotionally and financially. They continued to perceive stigma from others over time, and felt that they had few resources for support or intervention. Those resources that they could identify were often seen as unsatisfactory in quality.

Even though research suggests that families do tend to adapt to having a child with autism over time, parents’ concerns for their children’s quality of life, education, activities, friendships, and independence are significant (Lee, Harrington, Louie, & Newschaffer, 2008; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008), and experiences of loss may be quite considerable (O’Brien, 2007). Young adulthood often presents a new set of challenges. Krauss, Seltzer, and Jacobson (2005) compared the perceptions of mothers whose adult offspring with autism were living with them to those of mothers whose adult children had transitioned to out-of-home residential settings. Mothers whose adult children lived with them appreciated the positive impact of this arrangement, particularly the ability to continue to be close to and enjoy the adult child. At the same time, however, significant negative impacts were identified, including the ongoing stress of managing problematic behaviors and confronting the continuing losses associated with having a child who did not traverse developmental milestones in a typical way.

In contrast, mothers whose adult children lived apart from them perceived the greatest positive impact to be on the child him/herself, in terms of opportunities for independence and continuing development, while citing negative impacts on the family in terms of being apart from the adult child. The researchers discussed the complexity and often ambivalent processes involved with caring for an individual with autism as he/she moves from childhood, through adolescence, and into adulthood.

Sibling relationships in families in which a child has autism carry similar rewards and challenges. Macks and Reeve (2007) compared the psychosocial and emotional adjustment of siblings of children with autism to that of siblings of typically-developing children. The presence of a child with autism in the family was associated with enhanced developmental outcomes for the typically-developing sibling, over and above the outcomes for the comparison group, when demographic risk factors were limited. However, as demographic risk factors increased (in this study, risk factors included being male, living in a family with low SES, and being the older child) siblings of children with autism experienced increasingly unfavorable outcomes, again over and above those of the comparison group siblings with similar risk factors.
As with parents, relationships between persons with autism and their siblings can remain complex even into adulthood. Orsmond and Seltzer (2007) compared involvement in the sibling relationship for adults with a sibling with autism to that of adults with a sibling with Down syndrome. Siblings of adults with autism had less contact with their siblings, reported less positive emotion in the relationship, felt more pessimistic about their siblings’ futures, and were more likely to state that their relationships with their parents had been affected. Siblings reported specific concerns about what would happen when their parents were no longer able to care for their siblings with autism.

**Interventions: What helps?**

While there is no cure for autism, a number of treatment approaches, most often used in combination, have shown considerable promise. While no approach is effective for all children, researchers have identified principles and practices that seem to have a higher likelihood of success.

**General principle I: Early intervention.** Early intervention has been highly successful in addressing many of the behavioral manifestations of autism, increasing engagement, improving the quality of social interaction, and decreasing harmful, aggressive, or challenging behaviors. For example, Turner, Stone, Pozdol, & Coonrod (2006) found that children who were diagnosed early in life and who received language and educational therapies immediately upon diagnosis showed improvements in cognitive and language ability that were maintained at 9 years of age. Further, early diagnosis and intervention consistently predicted better developmental outcomes than did later diagnosis and intervention, even controlling for the quality of the intervention.

Because of the efficacy of early intervention, the American Academy of Pediatrics (2006) has recommended that all children be screened for autism and other developmental disorders during their routine medical checkups at 9, 18, 24, and 30 months.

**General principle II: Inclusion.** Interventions that are embedded in the child’s natural environments and routines, conducted in inclusive settings, and delivered by familiar persons, have been demonstrated to yield better immediate outcomes, be maintained for a longer period of time, and generalize to a wider range of situations and settings, than do interventions which are delivered in more typical “special education” settings. Bellini, Peters, Benner, & Hopf (2007) conducted a meta-analysis of 55 studies of school-based interventions for children and adolescents with autism spectrum disorders. They measured both immediate and extended outcomes. Few differences were found among interventions that were delivered in different ways—for example, through peers or with the child him/herself. However, statistically significant differences in outcomes were detected when the researchers compared interventions delivered in the child’s classroom setting with those in which the child was “pulled out” of the classroom and then returned. Interventions conducted in the classroom setting resulted in (a) behavior changes of greater magnitude, (b) generalization of new skills to a wider range of settings, and (c) longer periods of behavior maintenance after the end of the intervention.

Engaging parents as partners in implementing interventions has received considerable attention in the literature. In their review of research on this topic, McConachie and Diggle (2006) concluded that, while not definitive, it appears that such strategies can increase parental knowledge of autism, reduce parental stress and depression, and improve parent-child interaction as well as the child’s communicative skills. They recommended continued careful study of the issue, since, even for the 12 rigorous studies that they reviewed, methodological issues remained, including intervention fidelity and the degree to which parental involvement as a variable could be isolated from other factors.

In addition to these general principles, several intervention strategies show promise for children with autism. These are summarized below:

**Social skill interventions.** Since challenges with communication and interaction are among the most disabling for children with autism, these have, understandably, been a primary focus of educational interventions. In addition, it may well be that social interaction is one of the more malleable aspects of autism, with important implications for functioning, independence, and quality of life. Bauminger and Shulman (2003) interviewed mothers of children with relatively high-functioning autism to learn about the kinds of friendships that their children had.

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**Annotated Bibliography**

For more information on these and other references on this topic, please visit the Annotated Bibliography section of the FamilyTrends website (www.familytrends.org). This section summarizes the research literature and other helpful sources for a particular FamilyTrends Brief. Journals for Social Work, Psychology, Marriage and Family, Public Policy and other similar disciplines are referenced. This list will be updated periodically in order to capture the most recent literature.
formed, and the conditions under which this best occurred. Mothers described both mixed (child with autism and typically developing child) and non-mixed (child with autism and another child in special education) friendships. The researchers found that friendship does occur for children with autism, but most often required supportive environments and people for this to occur. For example, children with autism preferred more structured activities that required less conversation and social engagement than did their typically developing peers.

Social skills interventions can take several different forms, including

- Modifying the environment to promote and reward social interaction (monitoring the level of stimulation, providing structured opportunities for interaction);
- Training typically-developing classmates, playmates, or siblings to develop skills in engaging and interacting with their peers with autism;
- Working with parents as partners in intervention, training them to implement strategies aimed at improved interaction during the course of family routines and activities; and
- Working with the child him/herself, using behavioral interventions to reinforce desired social skills or training in social thinking/cognition and perspective-taking (understanding and responding appropriately to social cues).

Each of these strategies, alone or in combination has been found to yield positive outcomes (Bauminger, 2002; Bauminger & Shulman, 2003; Bellini, Peters, Benner, & Hopf, 2007; Gresham, Beebe-Frankenberger, & MacMillan, 1999; Harper, Symon, & Frea, 2008; Horner et. al, 2002; McConnell, 2002; Tsao & Odom, 2006). Some experts have recommended additional research efforts that will help to clarify our understanding of social skills interventions. Studies that focus on intervention fidelity, social validity, and an increased range of settings and contexts in order to better delineate the “fit” between intervention and the child have been recommended (Bellini et. al, 2007; McConnell, 2002).

Behavioral interventions. Behavioral interventions for children with autism focus on reducing harmful or undesired behaviors, as well as increasing desired behaviors. Applied Behavior Analysis strategies encompass a range of specific intervention techniques that are based on principles of operant conditioning, whereby antecedents (stimuli or triggers), the child’s behaviors, and responses to those behaviors (reinforcements) are components of a “chain” that serves to increase certain behaviors and decrease others (Erba, 2000; Horner et. al, 2002; Lovaa, 1987; Reed, Osborne, & Corness, 2007; Rosenwasser & Axelrod, 2001). Beginning with an in-depth assessment of those behavioral chains for the specific child, behavioral techniques focus on modifying the antecedents as well as the responses to the child’s behaviors in order to promote optimum skill mastery and development. After new behavioral chains are established, the focus often shifts to generalization of those new patterns to other environments and people in the child’s life.

Behavioral techniques have shown considerable promise in improving language and social interaction skills, reducing self-injurious behavior and aggression toward others, and improving attention. Horner et. al (2002) observed that behaviors identified via assessment as especially important to the child’s improved functioning were the most likely to be effectively addressed with behavioral interventions. Part of this assessment included a detailed understanding of the environment in which the behavior occurred, including factors that preceded the behavior, maintained it, and/or altered it. Strategies implemented by parents, teachers, and other caregivers in the child’s natural environment were likely to be effective as well. Horner et. al suggested that research on the manner in which the positive outcomes can be best generalized to other settings and maintained over time is less abundant, and is a crucial step in understanding the utility of these strategies for children with autism.

Multi-component interventions. A number of successful intervention programs for children with autism take a comprehensive approach, addressing cognitive, sensory, and social concerns through intensive intervention and support. Dawson and Osterling (1997) reviewed several multi-component early intervention approaches for children with autism, and identified common elements among them. They found that all of the programs contained the following:

- Instructional activities that focus on attending to, understanding, and responding to social and environmental cues
- Careful structuring of learning environments to provide controlled levels of stimulation, as well as predictability in the flow of schedules and activities
- Support for generalizing what is learned in the classroom to home and other natural environments; and
- Inclusion of family members as partners in the intervention process.

One of the best-known examples of a multi-component intervention is TEACCH (Treatment and Education of Autistic and related Communication-Handicapped Children), a comprehensive program for autistic children and adults. founded in the early 1970s by Eric Schopler at the University of North Carolina at Chapel Hill’s Department of Psychiatry. TEACCH remains based at the University, but has established a number of regional intervention sites throughout North Carolina.

Much progress has occurred in the diagnosis and treatment of autism spectrum disorders.
The TEACCH intervention model, Structured Teaching, is founded on an understanding of the patterns of thought and behavior that often characterize autism-spectrum disorders. Most notably, these include (a) the tendency to focus on small units of information (particularly visual), with less skill in combining or organizing ideas; (b) challenges with attention, particularly around disengagement from preferred activities and reengagement after a transition; and (c) challenges with social interaction and communication.

Structured Teaching focuses on skill development, as well as fulfillment of “fundamental human needs such as dignity, engagement in productive and personally meaningful activities, and feelings of security, self-efficacy, and self-confidence” (Division TEACCH, n.d.). Educational strategies are multifaceted, and include the development and implementation of individualized curricula, inclusion of families as partners in intervention, guided adaptation of classroom interventions to home and other natural settings, careful structuring of the physical environment, and the use of visual prompts and supports to foster understanding and mastery of daily schedules, tasks, and activities (Mesibov, Shea, & Schopler, 2005).

LEAP (Learning Experiences: An Alternative Program) is a similarly comprehensive program of intervention with children with autism, in that it incorporates home and classroom environments, partnerships with families, and a broad range of cognitive and social skills. This program is unique, however, in that its cornerstone is service delivery in inclusive educational settings that include children with autism and their typically-developing peers (Strain & Cordisco, 1994).

Some multi-component interventions utilize primarily play to address attentional, social, and cognitive development. One of the better-known of these is Floor Time, a semi-structured play intervention (Wieder & Greenspan, 1997) in which the child is guided through a hierarchy of developmental stages and tasks addressing self-regulation, engagement, communication, and shared problem solving.

While research findings are promising for multi-component interventions, experts have noted that much of the research in the field has been limited by small samples and intervention practices whose quality has been monitored to varying degrees. It is widely recommended that such research continue, and that it incorporate, to the extent possible, intervention and comparison groups, random assignment of children to intervention and comparison conditions, and close monitoring of the consistency and fidelity with which the interventions are implemented (Gresham, Beebe-Frankenberber, & MacMillan, 1999).

**Medications.** While there are no drug interventions that “treat” autism, various medications have been used with some success to address some of the issues and problems that tend to co-occur with autism spectrum disorders (National Institutes of Mental Health, 2007). For some individuals with autism, psychotropic medications have been shown to be helpful in addressing some of the behavioral and emotional symptoms of the disorder, including depression, obsessive-compulsive disorder, or anxiety. In addition, autistic persons with seizure disorders can be effectively treated with some typical anticonvulsant drugs, and the hyperactivity and impulsivity in autism can sometimes be successfully addressed with medications used to treat attention deficit disorder.

**Nutritional or dietary interventions.** Because of the research described above citing greater than usual sensitivity to environmental toxins and food allergens in children with autism, there have been efforts to design and implement interventions that focus on nutritional or dietary changes as a way to lessen the severity of autism symptoms. Curtis and Patel (2008) synthesized research addressing nutritional and environmental issues in autism, and the potential of dietary and environmental modifications. They cited numerous studies demonstrating that (a) avoidance of certain known food allergens, such as wheat gluten and artificial preservatives, and (b) nutritional supplementation, may provide moderate treatment benefits. They concluded that, most likely, nutritional interventions are not sufficient to serve as the sole treatment modality for autism, and recommended further research aimed at understanding the specific conditions and combinations in which such interventions may be optimally applied.

**Summary and Conclusion**

Much progress has occurred in the diagnosis and treatment of autism spectrum disorders. Numerous resources, both professional and informal, exist to support families in identifying and accessing the assistance that they and their children may need. For these reasons, many children with autism have the opportunity to grow into adulthood maintaining considerable independence and having the chance to experience many of the same developmental milestones, joys, and challenges as their typically-developing peers.

**References**


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About the Jordan Institute

Created in 1996, the Jordan Institute for Families is the research, training, and technical assistance arm of the School of Social Work at The University of North Carolina at Chapel Hill. The Jordan Institute is a nonprofit, nonpartisan organization that develops knowledge and promotes practices and policies that build supportive families and stable communities.

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